

Profiles of Met and Unmet Needs in People with Dementia According to Caregivers' Perspective: Results from a European Multicenter Study

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**Profiles of met and unmet needs in people with dementia according to caregivers’
perspective: Results from a European multicenter study**

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ABSTRACT

OBJECTIVES This exploratory study aimed at investigating profiles of care needs in people with mild to moderate dementia and examined variables associated with these profiles.

DESIGN A longitudinal international cohort study.

SETTING AND PARTICIPANTS The baseline data of 447 community-dwelling dyads of people with dementia and their caregivers from the Actifcare study were included for analysis.

METHODS A latent class analysis was applied to identify profiles of needs, measured with the Camberwell Assessment of Need for the Elderly (CANE) as rated by the caregiver. We examined (socio)demographic (e.g. relative stress scale; RSS) and clinical characteristics (e.g. neuropsychiatric inventory) associated with these profiles.

RESULTS Four distinct need profiles were identified through latent class analysis. These comprised a “no need” profile (41% of the sample), a “met psychological needs” profile (25%), a “met social needs” profile (19%), and an “unmet social needs” profile (15%). A larger impact of caregiving on the caregiver’s life as indicated by a higher RSS score was associated with the “unmet social needs” profile.

CONCLUSION AND IMPLICATIONS In this large European sample, there was a subgroup of persons with dementia with high “unmet social needs” whose caregivers simultaneously perceived high stress in their caregiving tasks. Identification of these profiles may help provision of appropriate support for these people.

Keywords: care needs, CANE, profiles, latent class analysis, dementia

INTRODUCTION

Dementia leads to increasing dependency in daily life activities and results in an increasing need for support and care. In the early stages relatively little support may be needed¹. This is often provided by the spouse or family as informal caregivers^{2,3}, who support instrumental or personal activities of daily living for several hours per week or per day. As dementia progresses, the capacity for providing informal care may be exceeded and formal care (such as home nursing care⁴ or day care) may be required to ensure that care needs are met^{1,5}. Detailed needs assessment can therefore help understand the degree of support and help needed and subsequently ensure access to and provision of support⁶ and possibly need-focused interventions⁷. Previous European research⁸⁻¹⁰ in people with mild to moderate dementia and their caregiver showed that unmet needs (as measured by the Camberwell Assessment of Needs for the Elderly; CANE) were most frequently reported for memory, daytime activities, company and psychological distress. Unmet needs may be due to various factors such as a lack of awareness of available services, services being not sufficiently attuned to individual wishes or simply not provided in the right amount, refusal of the person with dementia, or having multiple behavioral or psychological symptoms, which can be distressing for informal caregivers, often the main provider of support for people with dementia living at home^{10,11}. Unmet needs in turn may cause adverse consequences such as a decreased quality of life of the person with dementia and caregiver^{8,11,12}, increased caregiver burden^{6,13}, and increased likelihood of nursing home placement¹⁴.

Studies that used the CANE mostly looked at individual need items or incorporated a sum score or percentage of met and/or unmet needs^{8,9,12,15}. No study has examined whether clusters of needs, as measured with the CANE exist and their possible association with sociodemographic and clinical factors. As unmet needs may lead to adverse consequences, this could be useful to identify subgroups with a high likelihood for a specific combination of unmet needs^{12,16,15}.

One such method for identifying subgroups or profiles is latent class analysis (LCA), previously used in cohort and survey studies to, for example, identify subgroups of service use in a population of community dwelling people with dementia and their caregivers ^{17, 18}, or identifying caregiver profiles of people with dementia ¹⁹ which further showed to be useful for predicting care use ²⁰. In addition, LCA has also been applied to study barriers in access to healthcare in community dwelling elderly, resulting in subgroups that could be meaningful for policy and provision of interventions ^{21, 22}.

The LCA approach in a population of people with dementia living in the community allows to identify subgroups with different needs, and to describe these subgroups based on their associated sociodemographic and clinical characteristics. This may lead to more effective tailoring of existing, or development of new, interventions that focus on broader need combinations. As these needs tend to cluster in individuals, integrated care approaches can be developed which are cluster- rather than need-specific, thereby taking their interrelatedness into account. The aim of this exploratory study was therefore to first explore which specific dyadic need profiles exist as reported by the informal caregiver. Second, several clinical factors of the person with dementia (e.g. MMSE) and (socio)demographic factors of both the person with dementia and their informal caregiver (e.g. social network) were used to further characterize these need profiles identified through LCA.

METHODS

DESIGN AND PARTICIPANTS

This is a cross-sectional study that uses baseline data from the Actifcare study ²⁴, which aimed at examining access to formal care in people with dementia and their caregiver, and developing

best practice recommendations. In the Actifcare study, 451 people with mild to moderate dementia and their informal caregiver from 8 European countries (United Kingdom n=76, Ireland n=43, Sweden n=50, Norway n=60, Portugal n=66, Italy n=53, Germany n=52 and the Netherlands n=51) were followed for one year. Recruitment of participants took place through various settings, such as general practices, memory services, community mental health services, but also via a call in local newspapers. Both the person with dementia and their caregiver provided informed consent. Participants were eligible if the diagnosis of dementia met DSM IV-TR criteria, the person with dementia did not use regular assistance from formal health and care services for personal care related to dementia (although expected to start using formal care within one year, based on clinical judgement), the person with dementia had a Clinical Dementia Rating (CDR) of 1 or 2 (indicating mild or moderate dementia) and/or a Mini-Mental State Examination (MMSE) ≤ 24 ²⁴, and there was an informal caregiver who was able (and willing) to participate. The full list of exclusion criteria may be found in the protocol paper²⁴. Formal care was defined as nursing care at home, day care services, community or long term medical, nursing and social care⁴.

ASSESSMENTS

Needs were measured with the Camberwell Assessment of Need for the Elderly (CANE²⁵ in an interview-based setting with the researcher, as validated in many other studies with people with dementia and caregivers^{9, 25-27}. The CANE incorporates a range of environmental, physical, psychological and social need areas²⁸ and consists of 24 need items (e.g. 'accommodation', 'self-care', 'psychological distress' or 'daytime activities') related to the person with dementia and two additional items for the caregiver needs ('information' and 'psychological distress'). Needs can be scored as 'no need', 'met need' or as 'unmet', according to different perspectives (the perspective of the person with dementia, the informal caregiver,

and the researcher, as in Actifcare). A met need constitutes a prevalent need that is being met by informal or formal care (e.g. needs and receives care regarding personal hygiene), whereas an unmet need constitutes a prevalent need that is not being met (e.g. needs care regarding personal hygiene, but does not receive (right) care). For this analysis we used the informal caregiver perspective to determine the level of need of the person with dementia, and we also include both informal caregiver-related need domains. Although all perspectives must be valued in needs assessment, the informal caregiver perspective is intrinsically important given the direct knowledge of the situation (e.g. associated needs), the potential for circular influences between the person with dementia and their caregiver, and a consensus in this field which is to alleviate informal caregiver burden whenever trying to improve the provision of care ²⁹.

Because of the explorative nature of this analysis, no hypothesis was defined *a priori* and therefore a selection of various clinical and (socio)demographic variables was included that ranged from variables directly related to the person with dementia to variables related to the informal caregiver.

SOCIODEMOGRAPHIC CHARACTERISTICS OF THE INFORMAL CAREGIVER

The social network of the caregiver was assessed through the Lubben Social Network Scale (LSNS), ranging between 0-30 ³⁰. The impact of caregiving on the caregivers life was measured with the Relative Stress Scale (RSS), ranging between 0-60 ³¹, and depressive symptoms of the caregiver were measured with the depression subscale of the Hospital Anxiety and Depression Scale (HADS), ranging between 0-21 ³². Informal (unpaid) care provision was measured by the Resource Utilization in Dementia (RUD) instrument including the amount of informal care for Instrumental Activities of Daily Living (IADL; such as support with household activities) and Basic Activities of daily Living (BADL; e.g. help with self-care) for the last 30 days.

CLINICAL CHARACTERISTICS OF THE PERSON WITH DEMENTIA

Clinical characteristics of the person with dementia included cognition, measured with the MMSE, ranging between 0 – 30 ³³; activities of daily living, measured with the IADL (ranging between 0 - 8) and Physical Self Maintenance Scale (PSMS; ³⁴), ranging between 0–6; and neuropsychiatric symptoms measured with the Neuropsychiatric Inventory Questionnaire (NPI-Q; ³⁵), ranging between 0-36. The IADL, PSMS and NPI-Q were completed by the informal caregiver. The presence and amount of comorbidities were measured with the Charlson Comorbidity Index ³⁶. In case a questionnaire was not available in all languages, the questionnaire was translated and back-translated to ensure validity ²⁴.

Finally, region of residence (north (Sweden and Norway), middle (United Kingdom, Ireland, Germany and the Netherlands) and southern Europe (Italy and Portugal)) was included as a dummy variable to adjust for possible regional variations.

STATISTICAL ANALYSIS

First, all 26 items of the CANE were assessed and included using a decision rule of having $\geq 10\%$ of unmet need responses per item at baseline. This was done to prevent infrequent response patterns ³⁷. Missing data on these need items were handled in Mplus by maximum likelihood estimation using all information available. In case of a full missing observation, case wise exclusion was applied.

Missing data on covariates was multiple imputed in Stata version 13 (StataCorp, TX) using chained equations, as missing data on observed covariates is listwise excluded/deleted ³⁸. Predictive mean matching was used for continuous variables and logistic regression for dichotomous variables. For each imputed variable a mean was created based on all imputed datasets and this mean was used in Mplus. In total, 15 datasets were created.

Latent class analysis

Latent Class Analysis (LCA) is a method used to group people in so called latent classes ³⁷, based on responses given. LCA assumes that there is an underlying unobserved categorical variable that separates the group into subgroups, or classes. Individuals that belong to a class have a particular combination of responses ³⁹, in our case responses of need or unmet need.

First, different models were fit in Mplus version 8 (Muthén & Muthén, 2017), starting with a one-class model and increasing the number of classes until the number of participants in one of the classes was smaller than 10%. Each k-class model, indicating number of classes, was examined on following criteria: 1) loglikelihood value, where larger values indicate better fit, 2) the sample size adjusted Bayesian Information Criterion (BIC), where smaller values indicate better fit and 3) entropy score, where higher values indicate more certainty and classification of individuals. The 4) Vuong Lo Mendell Rubins test and 5) bootstrapped likelihood ratio test were applied to examine k-1 model versus k-class model, using a value of <0.05 indicating rejection of k-1 class model ⁴⁰. For each k-class model, increasing random start values were applied, avoiding occurrence of local optima, or e.g. local solutions as described in the approach of Asparouhov, Muthén ⁴⁰. LCA is a data driven approach and therefore the last step comprised 6) checking face validity of final class model. This was done by visualizing the conditional probabilities, or probability of an individual in a given class endorsing a given item (e.g. a % probability of perceiving an unmet need) ¹⁷. These probabilities were defined as high in case 70-100%, moderate in case 40-69% and low in case $<40\%$ ⁴¹.

Regression analysis

After the identification of the number of classes, regression analysis was performed by adding the covariates as auxiliary variables to the LCA model using the R3STEP command (^{42, 43}; ‘R3STEP’). Due to the many covariates and explorative nature, the following procedure was performed. First, correlation analysis was performed on continuous covariates (independent variables), excluding them in case of moderate (≥ 0.5 or ≤ -0.5) to high correlation with another covariate. Second, univariable analysis was performed, excluding covariates in case of $p \geq 0.10$. The remaining covariates were included in a forward selection procedure, starting with the region (dummy) variable and adding variables one-by-one to the model. First, demographic variables of the person with dementia (gender, age, education and living alone or not) were included, followed by clinical variables (MMSE, NPI, comorbidities, IADL and PSMS) and last by variables related to the caregiver and social network (gender, age, education, spousal relation or not, HADS depression, LSNS-6, providing informal care IADL and BADL (RUD) and the RSS score). Each step involved adding the variable, running the model and evaluating the significance of the included variable. In case of $p \geq 0.05$, the variable was excluded during this stage until the final stage (model).

RESULTS

In total, 451 participants took part in the Actifcare study at baseline. Of these 451, three participants had no data available for the selected CANE items, and one had too many clinical variables missing. These were case wise excluded, leaving 447 participants for analysis. Demographic and clinical variables showed missing percentages less than 8% (see Handels, Skoldunger, Bieber, Edwards, Goncalves-Pereira, Hopper, Irving, Jelley, Kerpershoek, Marques, Meyer, Michelet, Portolani, Rosvik, Selbaek, Stephan, de Vugt, Wolfs, Woods,

Zanetti, Verhey, Wimo ⁴⁴ for a description) and most participants were only missing one variable (12%).

[INSERT Table 1 about here]

The following CANE items matched the inclusion criterion and were selected for the LCA (Table 2): daytime activities, memory, hearing/eyesight/communication, psychological distress, company, money/benefits, caregiver need for information and caregiver psychological distress. The remaining CANE items, such as self-care and physical health, were eventually excluded due to infrequent response patterns. Additionally, the ‘memory’ item was excluded due to the high amount of ‘met need’ (84%) responses, and very low ‘no need’ responses (2%), resulting in too little variation.

[INSERT Table 2 about here]

LCA

Models with 1 to 5 classes were fit. The 4-class model was considered superior based on model fit criteria (adjusted BIC and (bootstrapped) likelihood ratio test; Supplementary data S1 and S2)). Entropy score was 0.749, indicating acceptable classification certainty, superior to models with 1 to 3 classes. Based on most likely class membership, meaning individuals are assigned to classes based on the largest posterior probabilities ⁴⁵ (*only for descriptive purposes; not used in further analysis*), profiles were 41% (n=182), 25% (n=113), 15% (n=67) and 19% (n=85), for profile 1 to profile 4 respectively. Figure 1 shows these four profiles. Profiles were labeled according to their characteristics i.e. probabilities endorsing each item.

Members of profile 1 (“no need” profile) had a low probability of having a met or unmet need on each item.

Members of profile 2 (“met psychological needs” profile) had a moderate probability of having a met need for ‘psychological distress’ and ‘psychological distress of caregiver’. All items showed low probabilities for having unmet needs.

Members of profile 3 (“unmet social need” profile) had a high probability of having an unmet need for ‘daytime activities’ and ‘company’ and a moderate probability of having an unmet need for ‘caregiver need for information’ and ‘caregiver psychological distress’.

Members of profile 4 (“met social needs” profile) had a high probability of having a met need for ‘daytime activities’ and ‘company’ and a moderate probability of having a met need for ‘hearing/communication and eyesight’.

[INSERT Figure 1 about here]

Predictors of class membership

The “unmet social need” profile was chosen as the reference profile (Table 3), and compared with the “met social needs”, “met psychological needs” and “no need” profile. The Hospital Anxiety and Depression scale (HADS) depression score, Physical Self-Maintenance Scale (PSMS) score and years of education of the caregiver were not included due to moderate to high correlation with other covariates (Relative Stress Scale (RSS), Instrumental Activities of Daily Living (IADL) scale, informal care BADL, and education of the person with dementia). Age of the person with dementia and gender of the caregiver were not significant (>0.1) in univariable analysis and were also not included. Results of the final model, adjusted for region (dummy variable), are depicted in Table 3.

A lower RSS score, self-reported by the informal caregiver, was related to a higher likelihood of belonging to the “no need” profile as compared to the “unmet social need” profile (-0.11 ; $p < 0.001$). Providing more hours of informal care (IADL; 0.012 ; $p = 0.001$) and a lower RSS score

(-0.063; $p=0.015$) were related with a higher likelihood of belonging to the “met social needs” profile as compared to the “unmet social need” profile. In addition, region (north, middle or south) was associated with class membership. People from the southern region were more likely to be in the “no need” profile (1.60; $p=0.029$) or in the “met psychological needs” profile (1.68; $p=0.028$), and less likely to be in the “met social need” profile (-18.55; $p<0.001$). People from the northern region were only less likely to be in the “met psychological needs” profile (-1.82; $p=0.028$).

[Insert Table 3 about here]

Post hoc analysis

The HADS-depression subscale score correlated highly with the RSS (0.67; $p<0.001$) and was therefore eventually not included in the model for predicting characteristics associated with the need profiles. As depressive symptoms are an important issue ⁴⁶ a post-hoc analysis was performed including the HADS-depression subscale instead of the RSS, and using the “unmet social need” profile as reference profile. A lower HADS-depression score, self-reported by the informal caregiver was significantly associated with the “no need” profile (-0.183; $p=0.004$). Furthermore, both “met need” profiles also did show to have a higher HADS-depression score (0.267; $p=0.001$ and 0.156; $p=0.032$) compared to the “no need” profile, but did not significantly differ between the “met need” profiles and the “unmet social need” profile.

DISCUSSION

Four distinct need profiles were identified that differed regarding levels (no/met/unmet) and combinations of needs. The “no need” profile was largest (41%; based on most likely class),

which is in line with the Actifcare study population that comprised people with mild to moderate dementia who did not use formal care at baseline.

The “unmet social need” profile had a combination of highly prevalent unmet needs (15%), and was associated with a higher caregiver burden, reflected by a higher (self-reported) RSS score, and showed moderate to high probabilities for a combination of unmet needs. The areas of unmet needs and their frequency are comparable to those found by Miranda-Castillo, Woods, Orrell⁹ and van der Roest, Meiland, Comijs, Derksen, Jansen, van Hout, Jonker, Droes¹⁰, who also found daytime activities and company to be frequently assessed as unmet. This suggests that the social domain comprises an important area to be targeted by interventions in the mild to moderate stages of dementia. The majority of people with dementia live at home. A recent qualitative study conducted in Norway indicated that home care services mainly focus on physical needs²³. However, another central component of high-quality dementia care is about meeting psychosocial needs^{6, 7}. Therefore, it is also very important to target these specific psychosocial domains to make sure people with dementia can live at home for as long as possible²³. In previous articles, it was shown that (a higher number of) unmet needs was related to a lower health related quality of life^{8, 11, 12, 47, 48}. This furthermore highlights the importance of preventing or addressing these unmet needs in a timely manner.

One of the most prominent factors associated with belonging to the “unmet social need” profile, compared to the “no need” and “met social need” profile, proved to be a higher RSS score. Unmet needs on social and psychological domains may lead to a higher RSS score reflecting stress linked to lack of activities and isolation, burden and mood problems. Otherwise it could be that a higher RSS score (due to other factors like neuropsychiatric symptoms) leads to more perceived and reported unmet needs⁴⁹. In a post-hoc analysis including the informal caregiver self-reported HADS-depression subscale, results did show that people in the “no need” profile did have a lower score (i.e. less depressive symptoms), which is plausible and in line with

previous research ⁵⁰. However, no significant difference was found between the “unmet social need” profile and both “met need” profiles. In fact, both “met need” profiles showed a significantly higher HADS-depression score when compared to the “no need” profile, but did not significantly differ from each other. This suggests that both needs being met or unmet are linked to stress and mood problems in informal caregivers.

Although the impact of caring was perceived as higher in the “unmet social need” profile, hours of informal care were lower compared to the “met social needs” profile. Sutcliffe, Giebel, Bleijlevens, Lethin, Stolt, Saks, Soto, Meyer, Zabalegui, Chester, Challis ⁵¹ for example showed that increasing hours of informal care were associated with increasing levels of caregiver burden. However, causality is hard to determine based on the cross-sectional nature of this analysis. It is likely that due to more informal care hours being provided, a need is more likely to be met. Moreover, other factors could contribute to a better perceived RSS score, such as a social network and others who help with e.g. caregiving tasks. However, social situation (measured through the LSNS-6; informal caregiver self-reported) was not associated with any of the profiles, although this could have been expected. This could be due to the scale measuring frequency and size of network (family and friends) rather than the quality of the relationship ^{30, 52}.

Caregiving can impact the caregiver and could lead to an experience of caregiver strain and potential physical and mental health problems, known to be risk factors for institutionalization of the person with dementia ⁵³. Furthermore, as our results did show, there was a moderate probability for having an unmet need for information. According to a recent scoping review, provision of tailored information is considered a main area of support for informal caregivers of people with dementia ²⁹, and psychoeducational support could further reduce caregiver stress ⁵⁴. Although this work presented is explorative and the first of its kind, evidence suggests that specific need profiles could be targeted by psychosocial interventions that address multiple

needs. Although we identified homogeneous profiles in terms of similar need combinations, individual preferences regarding for example daytime activities still exist ⁵⁵. Therefore, the extent to which existing psychosocial interventions could potentially address this specific unmet need combination is difficult to estimate. Regarding the unmet needs profile, results suggest that an intervention comprising social activity components (e.g. day care) and a psychoeducational component ^{7 29, 54, 56} for the caregiver could address the combination of unmet needs, potentially also reducing caregiver distress. Additionally, a key contact person, if provided in a timely manner, could significantly facilitate adequate care, safeguarding these individual aspects ⁵⁷. More research is therefore needed to investigate the clinical impact of these findings e.g., whether different interventions are needed for specific group profiles such as those found in our study.

Strengths of this study include the large international country dataset that accounted for many different factors related to symptoms and (informal) care. Furthermore, the statistical approach used can be considered a particular strength. Such approaches have the benefit of gaining a better understanding of subgroups as LCA is a person centered approach capturing heterogeneity within and between groups ⁵⁸. Capturing this heterogeneity in prevalent needs and subsequently examining further determinants associated with specific need profiles, may contribute to more individualized dementia care ⁵⁹ by tailoring to these profiles. Limitations include the study sample being a convenience sample, which limits generalisation to the wider population. Secondly, the use of region (north, middle and southern Europe) as a dummy variable may be considered suboptimal as this does not reflect the country specific care system, and furthermore country differences may exist ⁶⁰. Third, need items can be experienced differently between caregivers and therefore do not specifically incorporate weights of importance, resulting in profiles where each need is interpreted as equally important. Fourth, although these profiles could lead to more tailored interventions, it should be kept in mind that

these need profiles are of limited use to examine eligibility to receive formal services, because of the use of needs as reported by the caregiver. Furthermore, several CANE items were excluded due to low responses of unmet needs, which in turn led to a reduction of indicators for the LCA. This was to prevent infrequent response patterns, but has the disadvantage of neglecting other domains where unmet needs could still exist. Although it was expected that the vast majority of participants would require care within one year this was not the case, as was reflected by the relatively low amount of identified needs. One methodological consideration concerns the multiple imputation of covariates. Although the method can be considered robust, and the amount of missing data was low, this is something to keep in mind when interpreting the results. A first recommendation for future research comprises the examination of need profiles over time, to see if and how profiles evolve, and better understand the cause of unmet need profiles. Secondly, it would be important to cross-validate need profiles in a general population of people with dementia.

CONCLUSION AND IMPLICATIONS

Within a multinational sample and considering the informal caregivers' perspectives, four distinct need profiles were identified in people with mild to moderate dementia who did not use formal care at baseline. Among these profiles, the "unmet social needs" profile showed to be a subgroup that was related to caregivers perceiving higher amounts of stress in caregiving tasks. Findings further highlight the importance of identification and provision of appropriate support, possibly by addressing these specific combinations of unmet needs. Addressing unmet needs could lower the impact of caring, help continued care at home for longer, and could potentially prevent a decrease in quality of life due to these unmet needs in both the person with dementia and the informal caregiver.

CONFLICT OF INTEREST

There are no conflicts of interest.

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Table 1: Characteristics of the person with dementia and informal caregiver at baseline (n=447)

Characteristic	Mean (SD), range or n(%)
<i>Person with dementia</i>	
Age	77.8 (7.9), 47 – 98
Gender, male n (%)	203 (45%)
Years of education	9.8 (4.5), 0 - 25
Living alone, n (%)	88 (20%)
PSMS (0 – 6)	3.7 (1.9), 0 - 6
IADL (0 – 8)	3.5 (2), 0 - 8
MMSE total (0 – 30)	19 (5), 3 -30
NPI-Q total (0 – 30)	7.7 (5.5), 0 - 30
Comorbidities, total	2.8 (1.8), 0 - 16
LSNS total (0 – 30)	16.6 (5.5), 2 - 30
CDR	
0.5	9 (2%)
1	342 (77%)
2	87 (19%)
3	9 (2%)
<i>Informal caregiver</i>	
Age	66.4 (13.3), 25 - 92
Gender, male n (%)	149 (33%)
Years of education	11.9 (4.4), 0 - 24
Relationship, spousal, n (%)	268 (60%)
RSS total (0 – 60)	21.2 (10.9), 0 – 49
HADS depression total (0 – 21)	4.8 (3.7), 0 - 17

PSMS, Physical Self Maintenance Scale; IADL, Instrumental activities of daily living; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; LSNS, Lubben Social Network Scale; CDR, Clinical Dementia Rating scale; RSS, Relative Stress Scale; HADS, Hospital Anxiety and Depression Scale

Table 2 Selection of CANE need items

CANE item	Included	Reason (if not included)
Accommodation	No	<10% unmet need
Looking after the home	No	<10% unmet need
Food	No	<10% unmet need
Self-care	No	<10% unmet need
Caring for someone else	No	<10% unmet need
Daytime activities	Yes	>10% unmet need
Memory	No	>10% unmet need; 83% met need and 3% no need. Too less variability.
Eyesight/hearing/communication	Yes	>10% unmet need
Mobility/falls	No	<10% unmet need
Continence	No	<10% unmet need
Physical health	No	<10% unmet need
Drugs	No	<10% unmet need
Psychotic symptoms	No	<10% unmet need
Psychological distress	Yes	>10% unmet need
Information	No	<10% unmet need
Deliberate self-harm	No	<10% unmet need
Inadvertent self-harm	No	<10% unmet need
Abuse/neglect	No	<10% unmet need
Behavior	No	<10% unmet need
Alcohol	No	<10% unmet need
Company	Yes	>10% unmet need
Intimate relationships	No	<10% unmet need
Money/budgeting	Yes	>10% unmet need
Benefits	No	<10% unmet need
Caregiver need for information	Yes	>10% unmet need
Caregiver psychological distress	Yes	>10% unmet need

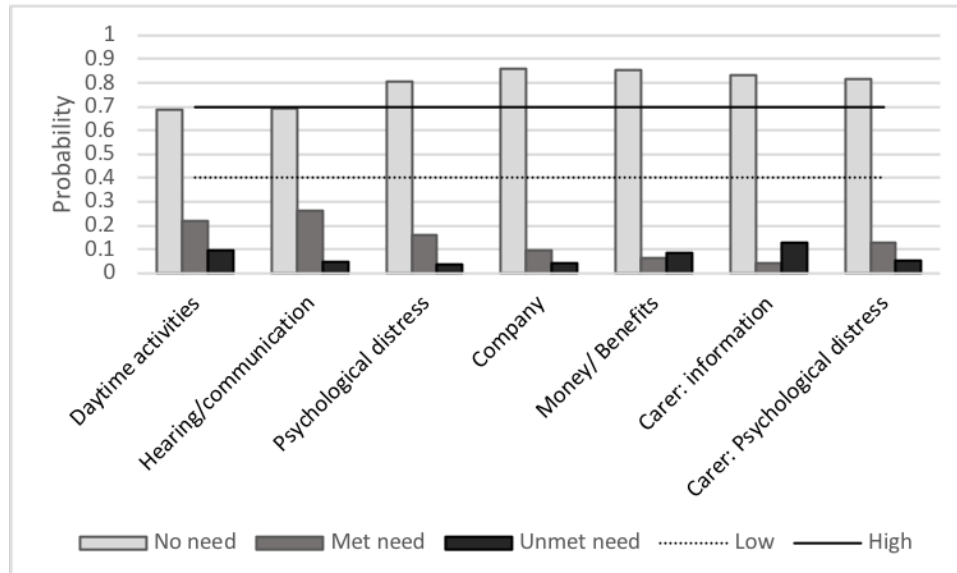
Table 3 Final model † showing predictors for class membership (estimate (sig))

	No need profile ‡	Met psychological need profile‡	Met social need profile‡
<i>(Socio) demographic</i>			
Education of person with dementia, years	-0.10 (0.052)	-0.091 (0.136)	0.085 (0.323)
Providing informal care IADL, hours	0.01 (0.059)	0.007 (0.058)	0.012 (0.001)**
RSS, total score	-0.11 (<0.001)**	0.011 (0.707)	-0.063 (0.015)*
<i>Clinical</i>			
MMSE, total score	0.07 (0.095)	-0.045 (0.409)	0.029 (0.523)
IADL, total score	0.11 (0.368)	-0.005 (0.976)	-0.251 (0.112)

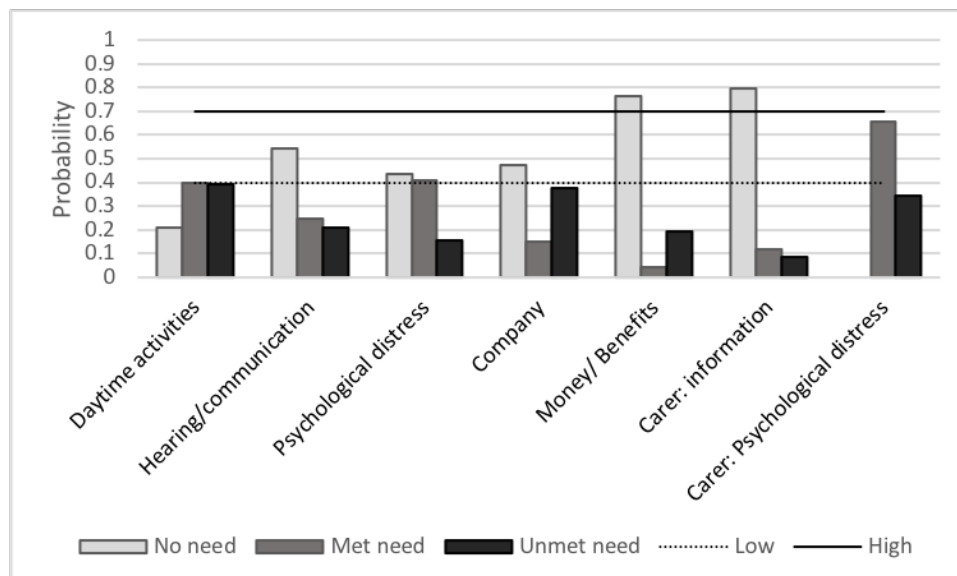
*<0.05; **<0.01; ‡ unmet need profile is reference profile; † results are only displayed for profile 1 vs 3, 2 vs 3 and 4 vs 3; Profile 1, “No need”; Profile 2, “Met psychological needs”; Profile 3, “Unmet social needs”; Profile 4, “Met social needs”.

Figure 1 Conditional probabilities including cut-off lines indicating low/moderate/high probability

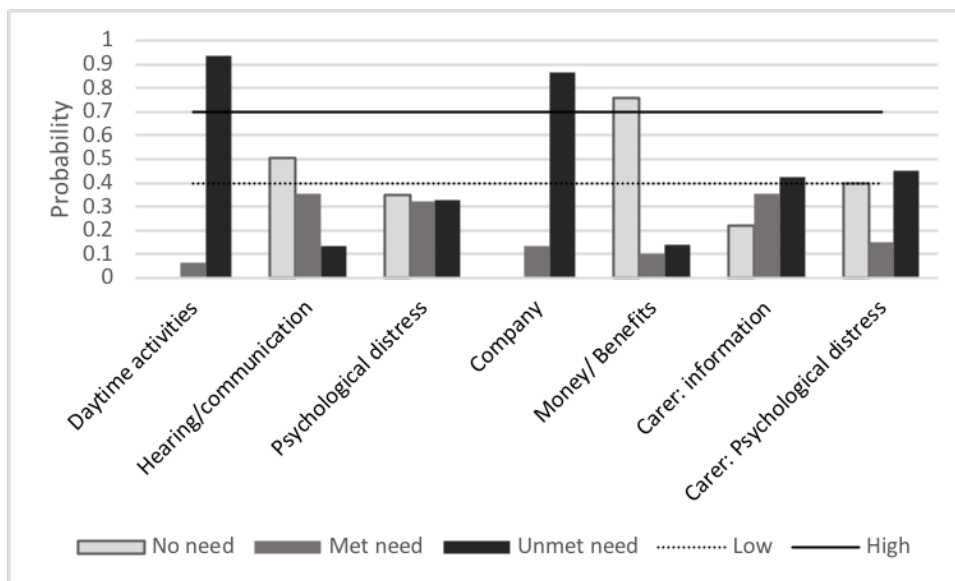
“No need”



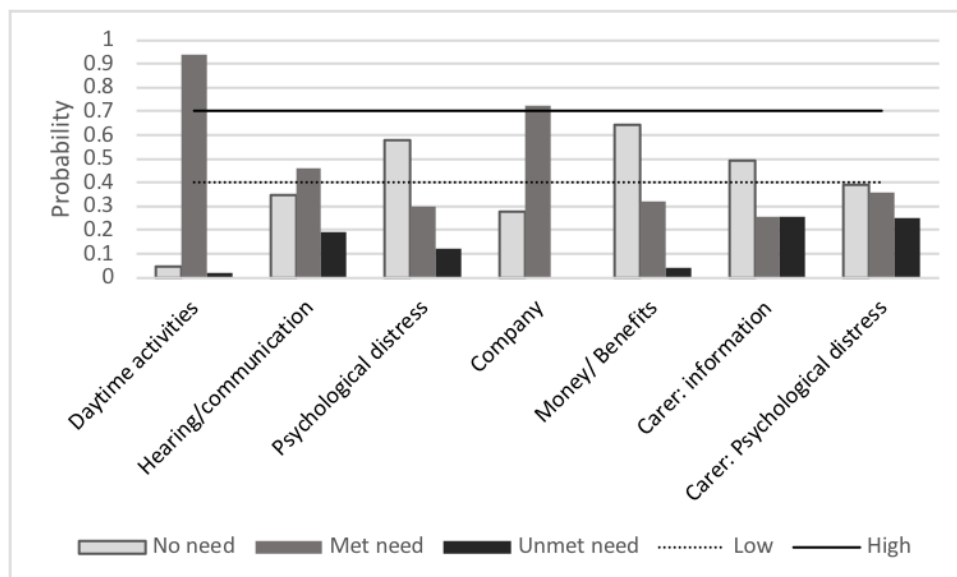
“Met psychological needs”



“Unmet social need”



“Met social needs”



S1 Fit statistics for Latent Class Model of needs

	1	2	3	4	5
<i>N free parameters</i>	7	29	44	59	74
<i>LL</i>	-1428.750	-2767.512	-2726.213	-2.698.319	-2681.602
<i>Adj. BIC</i>	5828.735	5619.964	5581.301	5569.446	5579.947
<i>LR Test</i>	-	<0.001	0.0017	0.0057	0.7166
<i>BLR Test</i>	-	<0.001	<0.001	<0.001	0.15
<i>Entropy</i>	-	0.669	0.715	0.749	0.768

LL, Log Likelihood; LR Test, Likelihood Ratio Test; BLR Test, Bootstrapped Likelihood Ratio Test

S2 Scree plot of adjusted BIC values between k-class models

